

DOCUMENT RESUME

ED 453 626

EC 308 434

AUTHOR Kulik, Barbara J., Ed.
TITLE Physical Disabilities: Education and Related Services,
Spring 2001.
INSTITUTION Council for Exceptional Children, Arlington, VA. Div. for
Physical and Health Disabilities.
PUB DATE 2000-00-00
NOTE 57p.; Theme issue.
AVAILABLE FROM Boyd Printing Co., 49 Sheridan Ave., Albany, NY 12210 (\$35
per year for individuals, \$75 per year for institutions, \$6
for a back issue). Tel: 800-877-2693, ext. 118 (Toll Free);
e-mail: qcorp@compuserve.com.
PUB TYPE Collected Works - Serials (022)
JOURNAL CIT Journal of the Council for Exceptional Children; v19 n2 Spr
2001
EDRS PRICE MF01/PC03 Plus Postage.
DESCRIPTORS *Academic Standards; Children; *Childrens Literature;
*Curriculum; Elementary Secondary Education; *Grief; Head
Injuries; Neurological Impairments; *Physical Disabilities;
Physical Mobility; *Severe Disabilities; Special Health
Problems

ABSTRACT

This volume of "Physical Disabilities: Education and Related Services" contains the following featured articles: (1) "The Value of Standards-Based Curricula for Students with Physical and Health Disabilities" (Catherine L. Keating), which discusses how a standards-based evidence-based curriculum can provide a basis of consistency for all children and raise expectations of students to meet the standards; (2) "Using Children's Literature To Help the Grieving Child" (Claire M. Thornton), which discusses how children understand death according to their cognitive development and how to respond to the needs of a grieving child as a parent or teacher utilizing children's literature; (3) "Active Fit Participation: A Model for Facilitating Programming for Individuals with Severe Traumatic Brain Injury" (J. Keith Chapman), which describes a model for making decisions about the environment and intervention options that will enhance the individual's ability to participate actively in functional programming; and (4) "M.O.V.E.: Raising Expectations for Individuals with Severe Disabilities" (D. Linda Bidabe and others), which describes the essential components and procedures of a functional mobility curriculum for individuals with severe physical disabilities. (Articles include references.) (CR)

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EC308434

VOLUME XIX
NUMBER 2
SPRING 2001

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JOURNAL OF THE COUNCIL FOR EXCEPTIONAL CHILDREN
DIVISION FOR PHYSICAL AND HEALTH DISABILITIES

PHYSICAL DISABILITIES: EDUCATION AND RELATED SERVICES

**VOLUME XIX NUMBER 2
SPRING 2001**

**JOURNAL OF THE COUNCIL FOR EXCEPTIONAL CHILDREN
DIVISION FOR PHYSICAL AND HEALTH DISABILITIES**

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Physical Disabilities: Education and Related Services is sent to all members of the Division for Physical and Health Disabilities (DPHD) of the Council for Exceptional Children (CEC). Application for DPHD membership can be made through CEC at 110 N. Glebe Rd. # 300, Arlington, VA 22201-5704 or (703) 620-3660. Subscriptions to the journal are available through Boyd Printing Company, Inc., 49 Sheridan Avenue, Albany, NY 12210 (800) 877-2693 x 118, qcorp@compuserve.com. Cost is \$35 per year for individuals, \$75 per year for institutions. Back issues are available for \$18 each.

Physical Disabilities: Education and Related Services is abstracted and indexed in *Current Index to Journals in Education (CIJE)*.

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PRESIDENT'S MESSAGE

THE VALUE OF STANDARDS-BASED CURRICULA FOR STUDENTS WITH PHYSICAL AND HEALTH DISABILITIES

CATHERINE L. KEATING

DPHD President

Providence College's elementary/special education teacher training program has spent over two years preparing for a state-mandated standards-based site visit review. This 3-day visit by a nationally recognized 4-member team will occur in the spring of 2001. In preparation for this new program approval process, our faculty has been required to attend numerous out of class all-day meetings which initially taught us what our state's beginning teacher standards might be. The words "might be" are used as these have been in continuous draft revision format. Additionally, numerous extended day and off-campus training sessions were attended by our department members.

As we move closer to our spring site approval visit, we, as a faculty feel enriched by the new learning that a standards-based performance-evidenced curriculum has given us. At the same time, we feel that we have had to take time away from our class preparation and our student-faculty advising duties simply because there are only 24 hours in a day. Although we as a faculty see growth on paper as a result of this performance-based assessment process, we all feel that the process "robs Peter (the student) to pay Paul (the state)."

Another concern that teachers have is the recognition that so many trends in education are "here today and gone tomorrow." That cliché proved true with "open space classrooms." Will standards-based performance-based portfolio-evidenced curriculum last or become another example for the cliché?

Our students feel pressure with this process as they grapple with the significant workload that a state standards and CEC standards-based portfolio require. Ultimately, both faculty and students have pondered the most important question of all. "Will this process truly improve the academic and social abilities of children and adolescents in the public schools?" The true

answer to this will be time and maybe improvement in statewide norm-referenced standardized achievement test scores. Both faculty and students recognize we may be improving the old by introducing the new. If this is what occurs then obviously we've grown and so have the new teachers and the children they teach. If the converse occurs, then unfortunately, we will be back to asking, "Should we throw the baby out with the bath water?"

My colleagues in the schools are also in a quandry about changes in the educational system. They are being required to give students standards-based tests which often require 3 one-half days of class time. Before and after school, they are forced to take time away from their class preparation and paper correction times to develop five-year plans for how they propose to improve their teaching abilities. Many veteran teachers are responding to this with "enough is enough" and choosing to retire or leave teaching for another career. If our experienced teachers, who unselfishly share their "pearls of practice" exit teaching, who will mentor our new teachers?

Looking at our own field of teaching children who have physical and health disabilities, how might this trend effect them? Certainly, adopting a standards-based evidence-based curriculum can provide a basis of consistency for all children. It can set a standard for children to have, but will this result in more learning and greater academic achievement?

Many children with physical and health disabilities require direct instruction from a teacher to input information in an alternative fashion and to process and prepare their responses. Some other children use output devices which, although state of the art such as Dynavox, take extra time to let the listener know what the student's response is. Thus, the direct instructional techniques needed by many POHI students may result in less curricular material being covered in a school day. For many POHI students, the school year is extended to a year-round program to afford them the opportunity to meet curricular demands. In other cases, the age at which a student will typically graduate is extended to 22 so as to allow the extra needed time for this special direct instruction.

I am sure that teachers of students with physical and health disabilities will feel the same time constraints and resistance to change that we feel at the college level. They will complain about the time needed to collect evidence showing that their students are meeting state-based standards. However, as teachers move into the process, I think they will be forced to think about the value of each assignment they give as it relates to their students achieving certain state standards. They will be forced to extend and expand their assignments more often than not to raise expectations to meet

the standards. I think that this will ultimately result in higher expectations for students with physical and health disabilities.

It is my firm belief that once they start to embrace the change, they will see as I now do that a standards evidenced-based curriculum provides students with a richer academic program. It gives them the opportunity to achieve at higher levels because the standards which they must meet are high.

In the final analysis, that is what we all want for our students—achievement at their highest level. Standards evidenced-based curricula for students with physical and health disabilities can only help us in providing them with an opportunity to reach their potential.

USING CHILDREN'S LITERATURE TO HELP THE GRIEVING CHILD

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ABSTRACT

Childhood is an experience of learning. It is a time of developing cognitively, growing physically, and maturing socially. If parents and teachers desire to have the children of today become the emotionally healthy, holistic adults of tomorrow, then every aspect of life must be considered as a "teachable moment"; even the most difficult one, death. Death is complex and confusing for children to understand, especially when it is the loss of someone close. This article focuses on how children understand death according to their cognitive development, and how to respond to the needs of a grieving child as a parent or teacher utilizing children's literature.

Children are confronted with experiences of death in a variety of ways. In this technological age of multimedia and global communications, children are exposed to the tragedies of the world almost instantaneously. Suicides, accidents, and violent acts impact their lives daily (Goldman, 1999). In addition, children may experience the loss a family member, peer, neighbor, or even a pet due to illness. Consider the following facts:

- Twelve percent of all childhood deaths are caused by guns in accidents, suicides, and murders. Eleven children a day are killed with guns.
- Auto accidents are the leading cause of accidental deaths of children. Drownings are second.
- In a school system of 6,000 students, an average of four students die a year.

- Twenty percent of today's children will have experienced the death of a parent by the end of high school. (Goldman, 1999, p. 3)

Death is very difficult for children to understand, especially the loss of someone close. This article focuses on how children understand death according to their cognitive development, and how others can respond to the needs of a grieving child utilizing children's literature.

HOW CHILDREN UNDERSTAND DEATH

How a child perceives death is directly related to his/her cognitive development (Worden, 1996). Piaget's Theory of Cognitive Development provides guidelines for children's thinking processes at various stages (Wadsworth, 1996). These stages are correlated with an approximate chronological age. However, Obiakor, Mehring and Schwenn (1997) state, "The developmental age of a child, not the chronological age, influences how the child reacts to someone's death" (p. 64). It is important to consider the individual's ability to understand. Children who are gifted may comprehend more than others their age whereas children who are developmentally delayed may understand less than their chronological peers. Even though the rate of progression through these stages may vary, all children experience them.

PIAGET'S SENSORIMOTOR STAGE OF DEVELOPMENT

0-2 YEARS

Cole & Cole (1996) summarize the Piagetian achievements of this stage as "infants learning to coordinate their sensory perceptions and simple motor behaviors. Infants begin to recognize the existence of a world outside themselves and begin to interact with it in deliberate ways" (p. 169).

Infants are curious about their environment. They delight in grasping an object, looking at it intently, shaking it, tasting it, and then watching it fall. A very patient adult usually retrieves it. The baby keeps repeating the experience and by doing so, learns to integrate the sensory perceptions of sight, hearing, taste, and touch with the motor behaviors.

Also, if an object drops and rolls out of sight, then the object no longer exists for the child. It is "all gone." After a time, with a little more maturity, the child realizes that the object is only out of the field of vision. As Goldman (1999) states, "Peek-a-boo or hide-and-seek are games that after six months help develop the concept that things and people exist even if we can't see them" (p. 42).

Interacting with the environment, as stated above, is only one of the major aspects at this stage. Babies must also bond with significant adults and acquire language. Significant adults promote language acquisition through monologues and experiences of socialization. They also provide for the infant's basic needs on a regular basis. The infants respond to these adults with facial expressions, visual tracking, vocalizations, and gestures of reaching towards them. Young infants use crying as a means of alerting adults to their hunger and need for dry diapers. Smiling is the means of letting adults know of their content. Infants do express emotions. As infants develop, vocalizations will include cooing, babbling syllables, and eventually the utterance of the first word around 10–12 months of age. Infants, however, in their recognition and interaction of a world outside themselves, are not able to comprehend death. As Kroen (1996) states:

A death in the family will interrupt the nurturing routines they are accustomed to. Feeding schedules may change, the mother may be absent for long periods of time; her touch and tone of voice may change. While infants may not be able to comprehend the meaning of what is happening around them, they will perceive changes and negative stimuli in their environment. (p. 13)

PIAGET'S PREOPERATIONAL STAGE OF DEVELOPMENT

2–6 YEARS

Children at this stage of development do not have a developed sense of time. They cannot perceive death as forever and irreversible. Rather, they understand death as temporary and reversible. Kroen (1996) indicates that children "may equate death with a form of sleeping. In their minds, the dead person still eats, breathes, and exists, and will awaken at some point and return to a full life" (p. 14).

Unfortunately, this is reinforced through television programming. Huntley (1991) comments that frequently either cartoon animations or characters on television shows die in one segment only to reappear the following week in a rerun. This type of experience does not support what an adult affirms is true about death. The child wants to believe what they see. They are left confused.

The confusion may also be due to the fact that children are literal and egocentric in their approach to life at this stage. For example, Grollman (1990) cites the following example:

A mother said to her son: 'You keep your bedroom like a pigsty. You will be the death of me yet.' The mother died shortly thereafter. The boy

suffered terrible guilt because he believed his sloppiness was the cause of her death. (p. 52)

The child may confuse the meaning of words. Take for example, the word, *wake*. Kroen (1996) states that a child may understand the word *wake* in a completely different way from adults.

A wake might seem like a part of death where the dead person is supposed to 'wake up'—more 'evidence' that death is temporary. Or children might hear the word 'wait,' meaning that if they wait patiently, the deceased will return. (p. 17)

Children at the Preoperational Stage of development perceive death as temporary and reversible. They are literal in their understanding of words, and believe the world exists only as they see it. The challenge for a caring adult is to communicate that death is a natural, irreversible, and final aspect of life. The adult must utilize a simplified vocabulary, age appropriate information, and honest responses to difficult questions.

PIAGET'S CONCRETE OPERATIONAL STAGE OF DEVELOPMENT

6–12 YEARS

Children at this stage of development do understand the concept of time. Therefore, they can realize that death is the irreversible and final aspect of life. They are no longer egocentric, but they are concrete and literal in their understanding of death. They concretize death by personifying it as an angel, ghost, bogeyman, or hooded figure with a scythe (Fitzgerald 1992; Grollman 1990). Children at this developmental stage believe that this tangible agent of death catches people who are old, severely ill, or not cautious. Since children perceive themselves as young, and in the early concrete operational period as never growing old, they feel safe from death catching them. In order to further guarantee self protection, they may become nutritionally conscious (in order to stay healthy) and safety cognizant (heeding all the warnings about dangers that adults have given) (Fitzgerald 1992; Goldman 1999; Kroen 1996). By following these personal measures, they feel safe.

Children are curious and inquisitive about death at this age. They want to know specific facts and biological details (Huntley 1991; Schaefer & Lyons 1986). As their direct questions are asked, adults may feel uncomfortable with how to answer them. Evasion, avoidance, and the use of euphemisms are not helpful solutions. These approaches will only instill confusion and greater anxiety (Grollman, 1990). It is best to listen attentively to their ques-

tions, and to respond in an open, honest, and caring manner (Costa & Holliday, 1994).

PIAGET'S FORMAL OPERATIONS STAGE OF DEVELOPMENT

12 YEARS AND OLDER

Young adults at this stage of development are able to think abstractly, reason, and comprehend death as an adult does. They view death as inevitable, universal, final, irreversible, and happening to anybody at any age (Obiakor, Mehring & Schwenn, 1997). Their questions will center on cultural and religious beliefs as well as emotional issues. As Kroen (1996) states:

Their understanding of death is comparable to an adult's, but their emotional state is one of constant turmoil and change. On one hand, because they embrace life so fully—and because they are convinced of their own immortality and omnipotence—it is difficult for them to accept death. On the other, the trauma of death is likely to send them deeper into emotional turmoil. Their reactions may vary widely and change abruptly. (p. 25)

A caring adult needs to be comfortable with his/her own emotions surrounding death and the fluctuating, intense emotions expressed by individuals 12 years of age and older. In addition to letting the young adult know of one's availability to talk about the experience, it is wise to suggest connecting with community resources: grief counselors, support groups, and/or pastoral personnel (Maierman, 1997). Each person is different and the amount of time needed to process the experience may vary (Costa & Holliday, 1994).

In summary, each child is a unique individual. In addition to age and intellectual development, there are other factors such as personality, emotional maturity, and culture which additionally impact how a child reacts to the loss of someone close (Charkow, 1998). The range of grief may vary from no reaction to devastation. The child may not be able to control the intense feelings, but s/he can control what is done with those feelings (Obiakor, Mehring, & Schween, 1997). It is important to remember that there is no right way to feel. Each child will grieve differently. A significant adult must be patient, for grief has no timeline. As Grollman (1990) states: "Healing is a process; recovery is a choice." The following chart summarizes emotional reactions to grief according to the child's developmental stage. It also offers guidelines for teachers and parents to help a child or young adult cope with the loss of a family member, relative, or peer.

CHART #1**Emotional Reactions To Grief and How To Help**

Developmental Stage	Characteristics	Reactions	How to Help
Sensorimotor (0–2 years)	Learning to interact with the environment	Perceive physical changes in their environment	Try to maintain normal feeding schedules, etc.
	Bonding with caretakers	Perceive changes in tone of voice, touch, etc. of caretakers	Be conscious that the child senses sadness, absence of usual caretaker, etc.
Preoperational (2–6 years)	Do not have a sense of time. Do not perceive death as natural, forever, and irreversible; rather as temporary and reversible.	Sadness Abandonment Anger Denial Regression Withdrawal Insecurity Loneliness Curiosity Bewilderment Moodiness Ambivalence	Take a nature walk and explain the life cycle of leaves, animals, etc. Encourage them to express how they feel.
	Egocentric	Guilt	Assure the child that it was not something s/he said or did that caused the death.
	Understand words literally	Confusion	Simplify vocabulary. Be honest.

CHART #1
Emotional Reactions To Grief And How To Help, Continued.

Developmental Stage	Characteristics	Reactions	How to Help
Concrete Operational (6-12 years)	Personify death	Anxiety Fear Insomnia Nightmares Vulnerability	Listen attentively to concerns. Encourage verbal expression.
	Understand finality	Sadness Anger Denial Abandonment Physical symptoms Fatigue Loss of appetite Hyperactivity Withdrawal Loneliness Helplessness Ambivalence Separation Anxiety Learning difficulties Inattentiveness Moodiness Imitation of parental response Aggression	Encourage the child to express his/her feelings through writing a letter to the deceased, poetry, clay modeling, finger painting, drawing, music, puppets, or physical activity of choice. Accept what is shared without judgment.
	Inquisitive about death	Confusion May ask gruesome questions	Encourage questions. Avoid the use of euphemisms.

CHART #1**Emotional Reactions To Grief And How To Help, Continued.**

Developmental Stage	Characteristics	Reactions	How to Help
Formal Operations (12 years and older)	Understand death as inevitable, universal, final, and happening to anyone at any age	Reenacts death with dolls or action figures Preoccupation with dead person Sadness Anger Abandonment Anxiety Denial Aggression Loss of appetite Exhaustion Social withdrawal Learning difficulties Inattentiveness Insecurity Loneliness Moodiness Idealization of the deceased	Discuss a way to remember the person: planting a tree, memorial fund, etc. Guarantee confidentiality of all discussions. Let the young adult know of your availability and willingness to talk. The choice to do so must rest with the young adult. Never pry. Discuss a way to remember the person.

CHART #1

Emotional Reactions To Grief And How To Help, *Continued.*

Developmental Stage	Characteristics	Reactions	How to Help
	Emotional turmoil and intensity	Self-esteem issues Depression	Encourage the person to express feelings through creative arts or physical activity. Recommend that s/he connect with community resources (support groups, grief counselors, etc.).
	Questions on religious beliefs	Curiosity	Refer the person to pastoral personnel of his/her religious affiliation.

(Adler & Wingert, 1997; Brodtkin & Coleman, 1996; Charkow, 1998; Costa & Holliday, 1994; Cuddigan & Hanson, 1988; Ebeling & Ebeling, 1992; Fitzgerald 1992; Goldman 1994; Grollman, 1990; Huntley, 1991; Kroen, 1996; McGlaufflin, 1998; Maierman, 1997; Obiakor, Mehring, & Schwenn, 1997; Safranski, 1998; Schaefer & Lyons, 1986; Westmoreland, 1996; Worden, 1996).

UTILIZING CHILDREN'S LITERATURE

Children absorb information by observing, experiencing, and interacting with others. Parents and teachers are the primary role models for children and promote their holistic development. In order for children to acquire a

healthy emotional foundation upon which to build their adult life, three things they need are:

- 1) to absorb a positive perspective on life from the adult modeling that they have observed (Grollman 1990; Hochbaum 1999; McGlaulin 1998)
- 2) to learn to express and accept their feelings in good times as well as in difficult ones (Huntley, 1991);
- 3) to sincerely emulate a sensitivity in their interactions with others. (Charkow 1998; Cuddigan & Hanson 1988).

Both parents and teachers can assist children in attaining this healthy emotional foundation.

Children's literature is not a substitute for the needed interaction and role modeling with significant adults (Cuddigan & Hanson, 1988). Rather, it can be a valuable medium to use in initiating dialogue about the death of a family member, neighbor, peer or pet. It can provide the opportunity for vital 'teachable moments.' The guidelines in Chart #2 are for parents and teachers who may wish to use children's literature for this purpose.

After the story has been read, children might ask questions or discuss feelings which have emerged as they identified with the characters. Parents

CHART #2

Guidelines For Using Children's Literature

-
- Always preview the book before using it to make sure that it is appropriate.
 - Prepare appropriate questions that may be interjected ahead of time.
 - Before the child reads the book, initiate a discussion about feelings. Assure the child that feelings are not good or bad, and that it is "ok" to feel them.
 - Emphasize that each person chooses how to handle his/her feelings. There are healthy and unhealthy ways of coping with what one feels. Give examples to clarify healthy and unhealthy coping strategies.
 - Ask the child to explain his/her concept of death. This will confirm and disclose the child's developmental stage, and will help the significant adult to focus on the appropriate aspects.
 - Introduce the book and its major points.
 - If this is a classroom experience, make sure that you have communicated with the grieving parent(s) beforehand. Allow them to read the book and to discuss any concerns that they may have.
-

(Cuddigan & Hanson 1988; Grollman 1990; Huntley 1991)

and teachers can help the children to understand that feelings need to be named, accepted, and released in a manner that is appropriate. Most importantly, feelings are "okay." When the hurt is deep, the feelings are intense. Parents and teachers might share their own feelings or experiences around a loss. This, however, will reveal their own comfort level with sharing profound feelings (McGlaufflin, 1998). If they have not been able to grieve and express their own deep emotions surrounding a loss of someone close to them, then it becomes awkward for them to model and assist others in expressing healthy emotional responses. Parents and teachers need to be aware of their past experiences that could impact the present (Grollman, 1990).

Another reason why parents and teachers could experience awkwardness around modeling and assisting others with grief might be that they have not lost someone close to them. Therefore, the grieving process is an unknown entity. If this is the case, both the adults and children grieve together, openly sharing their feelings. One way to ease the loss is to remember in a special way the person who died. This could include planting a tree or a flower garden in the person's memory, or, establishing a memorial fund for scholarships, research, or a favorite charity. It is important to involve the children in the memorial decision; let them offer suggestions. Lastly, children's literature opens one's eyes to the experiences of others. It can sensitize children as to how others feel and can challenge the egocentricity of the young child. Awareness can improve interpersonal relationships with peers. Observing positive adult role modeling, the acceptance of feelings, and sensitivity in interactions with others are vital for children's holistic emotional well being. Utilizing children's literature as a medium to discuss death can assist significant adults in preparing children to become healthy adults of tomorrow.

HOW TEACHERS CAN ASSIST PARENTS

Parents and teachers need to network with each other to help a grieving child. Communication between the home and school guarantees consistency and stability for the child. The communication guidelines in Chart #3 are for teachers who have lost a member of the class or who might have a grieving child within their classroom.

CHART #3**How Teachers Can Assist Parents**

If a child has lost or is losing a family member:

- Contact the parent(s) to express your concern/sympathy. This will initiate dialogue and open the channels of communication.
- Offer to meet with the parent(s) to discuss concerns they may have regarding how to help the child.
- If the parent(s) would like to utilize children's literature to initiate a dialogue about the topic of death/dying with the child, prepare a list of age appropriate books.
- Discuss if the parent(s) would like you to address the topic of death/dying with the class. If so, disclose how you will proceed so that they can reinforce the experience at home.
- If the parent(s) would like to know about community resources (i.e. support groups for grief, grief counselors, videos, etc.), prepare a list that could be shared.
- Continue to keep in contact with the parent(s).

If a classmate has died:

- Contact the grieving parent(s) to express your concern/sympathy. This will initiate dialogue and open the channels of communication.
 - Ask the parent(s) of the deceased if you may let the other parent(s) know.
 - If the classmates' parents and grieving parents would like to utilize children's literature to initiate a dialogue about the topic of death/dying with their grieving child(ren), prepare a list of age appropriate books.
 - Discuss if the grieving parent(s) and classmates' parents would like you to address the topic of death/dying with the class. If so, disclose how you will proceed so that they can reinforce the experience at home.
 - If the grieving parent(s) and classmates' parents would like to know about community resources (i.e. support groups for grief, grief counselors, videos etc.), prepare a list that could be shared.
 - Continue to keep in contact with the grieving parent(s).
-

(Ebeling & Ebeling, 1992)

CHILDREN'S LITERATURE

Below is a list of children's literature books that address specific developmental aspects of Piaget's Cognitive Development. The italicized words in the summary indicate the correlation to the developmental aspects.

PIAGET'S PREOPERATIONAL STAGE OF DEVELOPMENT

(AGES 2–6 YEARS):

Children in this stage do not perceive death as natural, forever, and irreversible. The following books were chosen to help adults explain the concept of death and to help children identify and process their feelings.

- Clifton, Lucille. (1983). *Everett Anderson's Goodbye*, New York, NY: Holt. (Ages 3–8).

Everett Anderson's father has died. The illustrations emulate the feelings of the five stages of grief: denial, anger, bargaining, depression, and acceptance. Through a visual medium the child can *identify the feelings* and stages of grief.

- Mellonie, Bryan. (1983). *Lifetimes: The Beautiful Way to Explain Death to Children*. New York, NY: Bantam. (Ages 4–8).

Death is explained through a correlation with the lifecycles of birds, fish, insects, animals, and, lastly, people. For each, there is a beginning and an ending. In between, there is living. This book helps children realize that *death is a natural and universal* part of life.

- Mills, Joyce C. (1993). *Gentle Willow: A Story for Children About Dying*. New York, NY: Magination Press. (Ages 4–8).

"*Gentle Willow* was written for children who may not survive their illness and for the children who know them. . . . The characters *address feelings* of disbelief, anger, and sadness along with love, compassion, and care-giving. *Gentle Willow* provides children a 'transformational' way of viewing death and dying." (Introduction, p. i)

- Pellegrino, Marjorie. (1999). *I Don't Have an Uncle Phil Anymore*. Washington, D.C.: Magination Press. (Ages 5–10).

The young boy in this story describes the loss of his Uncle Phil. He relates the experiences of a wake and funeral along with the compassionate gestures of relatives and friends. He *learns from his observations of adults* how to be compassionate with his cousin, Jenny.

- Wilhelm, Hans. (1985). *I'll Always Love You*. New York, NY: Crown. (Ages 3–8).

A young boy describes the joy and mischief of his dog, Elfie. They grew up together. Except, Elfie grew much faster. As Elfie ages, the young boy describes how he tries to make Elfie more comfortable. One day, Elfie dies. The young boy is consoled by the fact that every night he told Elfie that he loved her. He realizes that it is important to *express your feelings*, and to let those you love, know you love them.

PIAGET'S PREOPERATIONAL STAGE OF DEVELOPMENT

(AGES 6–12 YEARS):

Children in this stage have numerous questions about death. The following books were chosen to help adults address their questions in an open and honest manner, and to help the children identify and process their feelings. Remember that at this stage, a child may experience guilt if s/he said or did something negative to the person prior to death.

- Cohen, Janice. (1987). *I Had a Friend Named Peter*. New York, NY: William Morrow and Co. (Ages 5–10).

Betsy's friend, Peter, dies in an accident. Her parents explain death to her in a *simple, honest, and open manner*, without *euphemisms*. She learns that Peter will always be a part of her life through memories.

- Holden, L. Dwight. (1989). *Gran-Gran's Best Trick*. Washington, D.C.: Magination Press. (Ages 4–12).

This book is sensitively written. It describes the *concrete* aspects of death that puzzle children. In addition to addressing the feelings, memories, and struggles surrounding grief, . . . "it is about how those we love never leave our hearts. That is love's best trick." (Introduction, p. i.)

- Grollman, Earl. (1990). *Talking About Death: A Dialogue Between Parent and Child*. Boston, MA: Beacon. (Ages 5–10).

This book has a read along text in which an adult can insert the name of the deceased. It explains death in a *simple, honest, and open manner*, without *euphemisms*. It also touches upon the issue of *guilt* which may be experienced if something was said or done by the child prior to the person's death.

- Moser, Adolph. (1996), *Don't Despair on Thursdays! A Children's Grief-Management Book*. Kansas City, MO: Landmark Editions, Inc. (Ages 4–10).

Grief is explained as a *process* with *no time-line*. It also offers positive, practical suggestions for how to handle the feelings which are experienced.

- Rogers, Jacqueline. (1986). *The Saddest Time*. Morton Grove, IL: Albert Whitman and Co. (Ages 6–10).

This book offers three short stories of loss: An uncle who dies of illness, a peer who dies from an accident, and a grandmother who dies in the hospital. In addition to the feelings of grief which are expressed, each story focuses on *remembering*. Death is perceived as a *natural and inevitable* aspect of life.

- Romain, Trevor. (1999). *What on Earth Do You Do When Someone Dies?* Minneapolis, MN: Free Spirit (Ages 5–10).

This small book describes the feelings experienced when someone dies. It helps children *identify and name the feelings*, as well as recommending *healthy ways* of expressing the intense emotions. It also *sensitizes others* to the experience of loss. In addition, it suggests ways to *remember* the deceased.

• Vigna, Judith. (1993). *When Eric's Mom Fought Cancer*. Morton Grove, IL: Albert Whitman & Co. (Ages 6–9).

This story describes the changes a family experiences as one member of the household is seriously ill. Eric struggles with feelings of fear, sadness, loneliness, anger, and guilt as his mother struggles with the various phases of cancer treatment. It offers positive parental *role modeling*.

PIAGET'S FORMAL OPERATIONS STAGE OF DEVELOPMENT (AGES 12 AND OLDER):

At this stage the young adult understands the concept of death. The struggle is with learning how to handle the intensity and fluctuation of their feelings and possible questions regarding religious beliefs. It is important to have the young adult network with local and national resources.

• Gootman, Marilyn. (1994). *When a Friend Dies*, Minneapolis, MN: Free Spirit (Ages 12 and up).

This small text focuses on the emotional experience of loss. It deals with the *fluctuating feelings of the young adult*. It lists national organizations, *community resources*, and recommended readings.

Childhood is an experience of learning. It is a time of developing cognitively, growing physically, and maturing socially. If parents and teachers desire to have the children of today become the healthy, holistic adults of tomorrow, then every aspect of life of must be considered as a “teachable moment”; even the most difficult one, death. It is challenging, but the time to embrace this challenge is now.

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ACTIVE FIT PARTICIPATION: A MODEL FOR FACILITATING PROGRAMMING FOR INDIVIDUALS WITH SEVERE TRAUMATIC BRAIN INJURY

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ABSTRACT

The environment of many individuals with traumatic brain injury (TBI) presents many opportunities for learning and/or re-establishing developmental skills. However, those who have severe motor dysfunction associated with TBI frequently are unable to explore the world around them. The West Alabama Comprehensive Services (WACS) Program has addressed these limitations by developing a model for making decisions about the environment and intervention options. This decision process is a proactive approach that will enhance the individual's ability to actively participate in functional programming.

A traumatic brain injury (TBI) is a complex condition. As a group of conditions, open head injuries (i.e., skull is penetrated on direct contact) and closed head injuries (i.e., skull or dural covering of the brain is not penetrated) are the two primary types of TBIs, with closed head injuries constituting the majority of cases (Hill, 1999; Thurman, Alverson, Dunn, Guerrero, & Sniezek, 1999). Cause factors related to TBI across all environments and age groups are automobile or motor/bicycle-related accidents (51%), falls (21%), neglect/physical abuse (12%), and sporting injuries (10%) (Chapman, 1996; Savage & Wolcott, 1994; Turnbull, Turnbull, Shank, & Leal, 1999).

A study conducted by Graham and McIntosh (1996) estimated that on a yearly basis between 0.18% and 2.5% of the general population experience a TBI. Moreover, TBI is the number-one killer of individuals under the age

of thirty-four (Smith & Luckasson, 1992), with young males under the age of eighteen having the highest incidence rates across age groups experiencing a head injury (Turnbull, Turnbull, Shank, & Leal, 1999). Data reported by Hill (1999) and Rosman (1994) indicate that each year approximately five million children and youth experience a head injury. Of this number, about 165,000 will experience a head trauma severe enough to require hospitalization, and approximately 2% to 5% will develop severe neurological complications which will require individualized educational and/or habilitation/rehabilitation training in physical, cognitive and/or behavioral skills (Semlyen, Summers, & Barnes, 1998).

Problematic in attaining precise data regarding the number of individuals who are functionally affected by a TBI are the diverse definitions and guidelines for services (Katsiyannis & Conderman, 1994; Savage & Wolcott, 1994). To illustrate, Bigler, Clark, and Farmer (1996) noted that a number of states have taken a narrow focus regarding eligibility requirements for services, while other states interpret TBI more broadly. Recent educational-based data, from the *Twenty-first annual Report to Congress*, indicated that 11,914 students with a TBI (6 to 21 years of age) were served during the 1997–1998 school year. This represents an overall 12.89% increase from the 1996–1997 school year data (U.S. Department of Education, 1999).

For those who experience a TBI, a variety of symptoms can be displayed, the effects of the injury can vary greatly, and the rate of improvement can fluctuate (Michael & Finnegan, 1995). Each individual case involving a TBI is unique because the effects of the insult are dependent on the severity of the physical characteristics and the brain's movement within the skull during the trauma event. There can be a number of secondary complications (e.g., brain swelling) associated with a TBI (Farmer & Peterson, 1995; Hill, 1999). The physical consequences of the TBI are usually obvious; however, cognitive and behavioral consequences are often more subtle (Carney & Schoenbrodt, 1994; Iverson & Osman, 1999). The greater the severity of the TBI, the more likely there will be long-lasting changes in physical, cognitive, and/or behavioral functioning (DePompei, Epps, Savage, Blosser, & Castelli, 1998).

Initially, TBI is a medical disorder; however, over time TBI becomes a psychological, sociological, and an educational issue. Today, education is confronted with numerous conceptual, methodological, legal, and administrative issues related to meeting the educational, social, and emotional needs of students who have experienced a TBI (McGann, Werver, & Douglas, 1997; Savage, 1997). One of the major challenges is the provision of individualized and appropriate programming for children and youth who have

experienced severe neuromotor and physical disabilities as a residual of the neurological insult. Unfortunately, few teacher preparation programs are currently designed with components focused on providing competency-based preparation regarding TBI across the life-span (Savage, 1988, 1991; Tyler & Mira, 1999).

West Alabama Comprehensive Services (WACS) is a center-based, community service program funded by the Alabama Department of Mental Health and Mental Retardation and The University of Alabama's College of Education, and operated through the Programs in Special Education. The center staff provides educational and habilitation/rehabilitation training for individuals who are (a) severely/profoundly disabled due to mental retardation, cerebral palsy, or other neurological impairment, and (b) are a resident of a 4-county west Alabama region. The major purpose of the WACS Program is twofold: (1) to provide individualized educational and varied community-based experiences to individuals with severe/profound physical and/or mental disabilities, and (2) to provide opportunities for conceptual and hands-on practicum experiences in working with this population for university graduate and undergraduate students who are majoring in general or special education, nursing, social work, psychology, and various other university-wide programs.

Of the 32 individuals presently receiving services at WACS, approximately 22% are identified as having severe physical involvement with related TBI. To better serve this population, the WACS Program recognizes that along with impaired motor functioning, many individuals with a severe TBI experience subsequent problems in cognition, language, behavior, and social adjustment. Within this context, the environment plays a major role in the ecological nature of programming. Specifically, the "adaptive fit" model incorporated at WACS seeks to match the individual with the severe TBI and/or other physical disabilities with the appropriate environment in order to develop and manage activities (Chapman, 1996). This process is ongoing with diverse strategies and continuous adjustments between the individual and the environment being evaluated and changes implemented in order to foster a supportive and positive program.

MODEL OVERVIEW

It has long been understood that individuals learn by acting on their environment. Unfortunately, in many cases TBI reduces access to opportunities for controlling events during educational or habilitative/rehabilitative pro-

gramming that would promote and/or help re-establish functional development (Singer, Glang, & Williams, 1997; Wall, Rosenthal, & Niemezura, 1998). For example, the inability to gain access to items or situations of interest may prolong or negate the reestablishment of cognitive, communication, social, and self-help skills. In addition, the key element of motivation of the individual seeking interesting activities may diminish. Seligman (1975) has argued that individuals with physical disabilities exhibit attitudes of extreme passivity that significantly inhibit their ability to control important events in their lives.

When TBI restricts the individual's abilities to engage the environment, compensatory procedures that maximize active involvement in their developmental programming become necessary. The *active fit participation* model represented in Figure 1 is employed by the WACS staff to guide decisions related to interventions that facilitate individualized participation, planning, and evaluation in programming activities. Operationally defined, *participation* means taking part in program activities, and *active fit* means to participate by first choosing, then manipulating, engaging, and interacting with the environment.

DECISION PROCESS

To facilitate active participation, the model's decision process begins with first identifying pertinent individual or group activities from the individual education plan (IEP) or individual habilitation plan (IHP). Then a two level evaluation procedure is employed to identify current conditions affecting participation and abilities affecting participation. The conditions affecting individual functioning within the environment are identified through review of medical records, physical therapy, orthotic, or other related agency evaluations, and consultations with the individual with TBI, parents or guardian, and primary instructors. Important areas of consideration are body positioning, assistive technology and equipment employed, muscle tone, and visual access.

Barriers to participation are also identified through review of the most recent developmental assessment results, recommendations, and consultations with the individual with TBI, parents or guardian, and primary instructors. Barriers are identified and organized by developmental capacities: (a) motor, (b) communication, (c) cognitive/learning, (d) sensory, and (e) social. This information is reviewed quarterly or as needed.

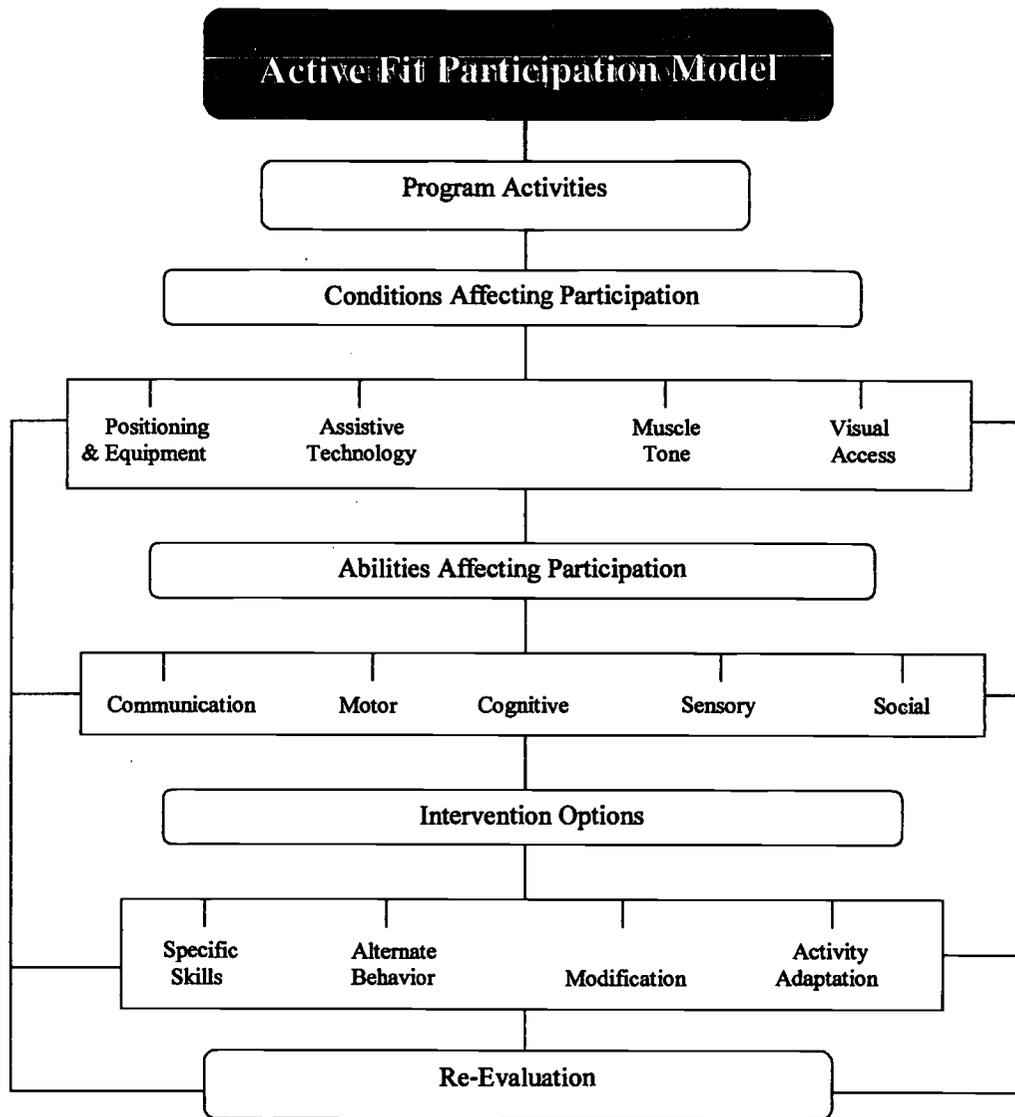


Figure 1.

The decision process approach to problem solving focuses on incorporating conditions (e.g., assistive technology) and removing barriers (e.g., inadequate field of vision) to participation in varied activities, thus increasing the likelihood of successful outcomes. For example, the individual's participation might be low in swimming activities if the associated motor impairment prevents functional participation. In this situation, the individual is limited to passive participation. However, if the individual chooses, he or she could be changed into a swimsuit, be placed on a raft, and although closely supervised, could manipulate, engage and interact with the environment and peers, thus becoming an *active fit participant*.

INTERVENTION OPTIONS TO ACTIVE FIT PARTICIPATION

The evaluation process provides the basis for selecting an intervention option(s) to be employed. The WACS decision process addresses four intervention options for incorporating environmental conditions and overcoming barriers to active program participation:

1. *Teaching specific skills* enables the individual to learn or re-establish developmental capacities using typical behaviors and conditions that can lead to both increased competence and independence.
2. *Reinforcing the individual's use of alternate, more adaptive behaviors*, which are already in the individual's repertoire to reinforce typical behaviors, can facilitate the habilitation or rehabilitation process. Alternative behaviors are only useful to the degree that they are functionally similar to the original target behaviors.
3. *Modification of the condition* is employed in two primary situations in working with individuals with TBI. First, the environmental condition may be unsuitable for the program activity. For example, the individual's position in the wheelchair may be inappropriate, thus hindering his/her ability to functionally participate. Modification of position may correct the problem. Secondly, the environment may be unsuitable due to the unique characteristics of the individual. For example, the individual may have visual problems that preclude focusing on activities at far distances. In this instance, the activity could be presented at a closer range using a computer stand.
4. *Activity adaptation* involves changing the materials or target task. Adaptations can be singular or multiple in nature and are made to a single activity based on instructor observations and strengths and needs identified in the IEP/IHP. Adaptation becomes an important option when there is a significant discrepancy between the individual's present level of functioning and the functional requirements needed to participate in the activity. For example, before the individual can learn to use a computer, he or she may need to learn to use a head wand or stick to operate the keyboard.

Individuals with TBI are constantly gaining and regaining skills across developmental areas. A major component of the model is the ongoing re-evaluation of each level. This enables the center staff to provide functional, appropriate programming through re-evaluating individualized participation, planning, and programming activities. This re-evaluation process also allows and encourages flexible and creative decision-making regarding such pro-

gram areas as diverse environments, service mix, and modifications in services.

CASE STUDY

The following case study illustrates an intervention procedure implemented by WACS staff employing the *Active Fit Participation* model. This study involved a 18 year old male who was in a car accident which resulted in a closed head injury with associated quadriplegic motor dysfunction. A number of group and individual activities aimed toward cause-and-effect learning were identified as important in his IEP. His vision was evaluated as functional; however, the primary identified condition affecting this learning process was his limited motor skills as he was not able to manipulate activity materials or move independently due to limited hand use or body movement. In addition, primary abilities affecting participation were his limited communication skills which prevented him from making choices or to interact in a functional manner in programming activities. His communication avenues were limited to either eye gaze or a communication board. Several interventions were identified to increase his ability to participate.

To increase his ability to manipulate activity materials, interventions regarding passive range of motion such as reach, release, and grasping skills to enhance hand-to-mouth feeding were initiated. To facilitate body movement, a pressure release program was initiated to enhance shoulder flexion and abduction, neck rotation, arm and elbow extension, and hip flexion. The individual was rotated every half-hour and his weight shifted every hour during programming. Several environmental modifications allowed him greater control over activity materials. For example, a nylon cord was placed on the items he was using during a certain activity. If he lost his grasp, he was able to help retrieve the item by slowly drawing the nylon cord.

Communication was also a target for intervention. Because of limited verbal expression ability, augmentative communication, specifically synthesized speech (power pad and computer), was identified and employed as an intervention option. This assistive device allowed him the opportunity to not only to make choices and interact during group and individual programming, but also enhanced his social interactions.

CONCLUSION

The effects of a TBI can be significant. The needs of the individual with a severe neuromotor TBI are often extraordinary and individually-specific. Educators and related service professionals can and should play important roles in meeting many of the academic, social, and emotional needs. This often requires a coordinated process of evaluating options for incorporating environmental conditions and overcoming barriers. One key element identified by Ylvisaker, Hartwick, and Stevens (1991) and Savage and McDonald (1999) in providing appropriate programming which fosters educational and social success is that proper orientation and training be available to the significant people in the individual's environment (e.g., teachers, related service professionals). Unfortunately, few teacher preparation programs currently provide competency-based instruction and/or field experiences in working with this population (Savage, 1988, 1991; Tyler & Mira, 1999). As reflected in recent data from the *Twenty-first Annual Report to Congress* (U.S. Department of Education, 1999), the number of individuals with TBI receiving educational services continues to grow. It is vital that the diverse and complex needs of this unique population be recognized as an emerging and important area of preservice and inservice training by teacher preparation programs.

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M.O.V.E.: RAISING EXPECTATIONS FOR INDIVIDUALS WITH SEVERE DISABILITIES

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ABSTRACT

The Mobility Opportunities Via Education (MOVE)[®] Curriculum is a functional mobility curriculum for individuals with severe physical disabilities. This paper presents the evolution of the curriculum in light of three main issues in the education of individuals with severe multiple disabilities: a) limited instructional time, b) reduced rate of learning, and c) lack of generalization of skills. Essential components and procedures of the curriculum are presented along with examples of applications. Support is provided through a description of the alignment of the MOVE Curriculum with current practices in the field such as support model, top-down curriculum, and integrated therapy.

One of the fundamental goals of educating students with severe disabilities is increased independence to promote integration into life activities (Snell & Brown, 2000). Individuals with severe disabilities have frequently been denied the opportunities to participate in typical life activities because of their inability to perform all necessary skills (Brown et al., 1979; Falvey, 1989). These individuals are often relegated to practicing prerequisite, infant skills in their educational programs rather than practicing relevant life skills (Attermeier, 1991; Rainforth & York-Barr, 1997). Unfortunately, this practice has typically resulted in isolation from peers, exclusion from many life

activities, and decreased opportunities to learn functional tasks (Falvey, 1989).

The current trend in the education of students with developmental disabilities has shifted from a deficit model in which the individual's limitations are emphasized to a support model in which future potentials are emphasized (Barnes, 1999). Educational programs that incorporate the support model provide more opportunities for individuals with severe disabilities to become active participants in life activities. One such program is the Mobility Opportunities Via Education (MOVE®) Curriculum.

MOVE® is a top-down, activity-based curriculum designed to teach children and adults with physical disabilities basic, functional motor skills needed within home, school, and community environments (Kern County Superintendent of Schools, 1999). The MOVE Curriculum is a naturalistic approach to teaching functional mobility skills that focuses on increased participation in normal activities of daily living. Rather than selecting skills from a developmental hierarchy, individuals using the MOVE Curriculum follow a top-down approach to program planning. Instructional activities and basic skills are selected based on functional outcomes, and instruction is incorporated into routinely occurring events dispersed throughout the day. A transdisciplinary team which includes parents, educators, therapists, and other professionals works collaboratively to assess the student's skills, design an individualized program, and teach the skills while the student participates in school and community activities. Every adult involved with the student is encouraged to take an active role in teaching the skills needed for sitting, standing, and walking.

There are six steps in using the MOVE Curriculum:

1. Testing
2. Setting Goals
3. Task Analysis
4. Measuring Prompts
5. Reducing Prompts
6. Teaching the Skills

The first three steps of the MOVE Curriculum form the foundation for deciding *what* to teach. In Step 1 the curriculum provides a Top-Down Motor Milestone Test™ (TDMMT) that identifies strengths and weaknesses in functional motor skill development (see Appendix A for the test summary sheet). The TDMMT is administered prior to implementing the MOVE Curriculum in order to identify each student's ability to use functional motor skills needed for typical sitting, standing and walking activities. As opposed to standardized, normreferenced tests, the TDMMT is a performance mea-

sure of an individual's actual use of mobility skills. A shift from the sole use of developmental measures of motor skills to measures of functional outcomes within natural contexts for program planning is highly advocated by current motor theorists (Attermeier, 1991; Fetters, 1991; Heriza, 1991; Heriza & Sweeney, 1994; McEwen & Shelden, 1995). Test items for the TDMMT were selected based on family, teacher, and therapist interviews that identified the most critical sitting, standing, and walking skills needed for independent functional mobility in adult life (Bidabe, 1998). There are no reliability and validity data available on the TDMMT; however, studies of instrument validation are currently in progress.

During administration of the TDMMT, the transdisciplinary team uses interview and observation techniques to determine if a student can consistently perform the specific behaviors necessary for functional sitting, standing, and walking within their natural environments. The parents and student are asked about functional use of the motor milestones beginning at the most independent level. This "top down" approach allows the team to (a) start with high expectations, (b) think in terms of functional abilities instead of deficits, (c) be aware of emerging skills, and (d) recognize target skills while identifying current performance. The team assesses the student at the highest level that indicates independent mobility. If the participant is unable to perform the skill at this level, the team then tests the individual at more supported levels.

For example, in Skill G "Walking Forward" the team would determine the level of assistance an individual would need to walk forward (see Appendix B). Starting at the most independent level, the team would ask if the child could walk forward a minimum of 20 feet without assistance. If the child was unable to perform this skill at the independent level, then the team would move down to the next level (i.e., can walk a minimum of 1000 feet with one hand held). This process would continue until the team determined the amount of support needed for performance of the skill.

In Step 2 the student's goals, both immediate and long term, are identified based on a family interview that addresses specific activities necessary for daily living that pose a challenge to the student and/or family. Once needs are identified, the transdisciplinary team selects priority activities to be addressed in the student's program.

In Step 3, the practitioners perform a task analysis to identify critical skills needed for participation in the selected activities. Data gathered during the TDMMT are used to select priority mobility skills to be embedded into daily activities. Although the MOVE Curriculum emphasizes functional mobility skills, the team also is encouraged to embed critical social, commu-

nication, and cognitive skills into activities to facilitate holistic programming. For example, within the functional activity of "eating lunch with peers in the school cafeteria," motor, communication, cognitive, social, and functional academic skills can be embedded (see Figure 1).

Whereas the first 3 steps of the Curriculum address *what* to teach, the last three steps determine intervention strategies or *how* to teach. Step 4 provides a process for measuring the amount and type of assistance or physical prompts a student will need in order to perform a task. This assistance can be provided by another person or with adaptive equipment. The MOVE Curriculum uses three prompt categories: (a) physical prompts for sitting, (b) physical prompts for standing and walking, and (c) physical prompts for arm control (Kern County Superintendent of Schools, 1999). Each of the categories is organized to specifically describe the type of assistance provided, prompt position, and the amount of assistance to be given (see Appendix C for an example of the prompt measurement system).

During Step 5, the team identifies areas where assistance can be faded as the student becomes stronger and more independent. After determining the current level of support needed in Step 4, the team identifies the specific prompts to be reduced to increase the level of independence within the activity. In the MOVE Curriculum, prompts are intended to be temporary supports that assist students in learning new skills. Students are given only as much help as they need to accomplish a task, and the assistance is faded as the student becomes stronger and more independent.

In Step 6, teaching strategies are identified for specific activities within the student's typical day. Practice opportunities are provided within natural environments promoting student motivation and generalization (Shelden, 1998). Motor skill practice is embedded into typical daily activities and integrated therapy is utilized to support teaching in natural contexts. Additional meaningful practice opportunities are also identified for each participant to provide the intensive practice required for students with severe disabilities who are at the acquisition level of skill development.

WHY WAS MOVE DEVELOPED?

In the late 1980's, educators within the Kern County School System began questioning the lack of progress of students with severe disabilities being served under the traditional bottom-up, developmental approach. In 1986, the Kern County Superintendent of Schools reported that based upon a review of student IEPs, the vast majority of students in Kern County, California with severe, multiple disabilities were leaving school at age twenty-

Activity-Based Instruction

Teaching skills through activities

<u>Activity</u>	Eating in the school cafeteria
<u>Skills</u>	
Communication	Respond appropriately to greetings, Make choices about food selections
Social	Wait appropriately in lunch line, Remain on task while in lunch line
Cognitive	Locate cafeteria
Functional Academics	Pay for meal
Motor	Walk to/from cafeteria in gait trainer (walk forward) Transfer to seat with assistance (stand to sit) Transfer to gait trainer with assistance (sit to stand)

Figure 1.

Example of activity-based instruction in which critical skills are embedded into a functional activity.

two with fewer motor skills than when they entered at age three (Kern County Superintendent of Schools, 1999). As a result of these findings, a more in-depth review of educational records as well as interviews with parents and staff was conducted. This informal investigation revealed three major programming issues believed to be related to this lack of progress: lim-

ited instructional time, reduced rate of learning, and a lack of generalization of skills (Bidabe, 1998).

The first issue focused on the way time was spent in special education classrooms for individuals with severe, multiple disabilities. Informal staff interviews related to class schedules revealed that the vast majority of classroom time involved a) moving students from one place to another, b) helping students eat and drink, and c) taking care of students' hygiene needs. A time analysis of classroom activities showed that after these basic needs were addressed, less than ten minutes per student was available for other instruction each day.

The second issue involved rate of learning. Learners with severe disabilities typically require increased time and increased repetitions to learn new skills (Beirne-Smith, Ittenbach, & Patton, 1998; Shelden, 1998; Snell & Brown, 2000). An analysis of student records indicated that these students often required extensive practice in order to gain new skills. Sometimes as many as 2,000 trials were required to master a new skill (Kem County Superintendent of Schools, 1999). A review of IEP goals and objectives indicated that the same skills frequently were being addressed year after year with little to no progress. In some cases, students showed a regression of skills. These educators concluded that as these children grew older and gained body weight, their weak muscles became less effective in moving their limbs against gravity. This resulted in the caregivers physically manipulating the students less, thus reducing the number of opportunities available for motor skill practice.

The third issue concerned the students' inability to generalize the skills learned in one environment for use in other environments. Research on generalization of skills has demonstrated that students with severe disabilities have decreased abilities to transfer skills learned in one environment to a different environment or different situation (Beirne-Smith et al., 1998; Campbell, McInerney, & Cooper, 1984; Shelden, 1998). Not only did students have difficulty applying similar skills in different settings, but they also experienced problems when additional variables existed. For example, students who were taught to roll down an inclined mat at school were not able to turn over in bed at home. Those who were taught to walk up wooden steps in the gymnasium were not able to step up to get on a school bus. The bed was not on an incline, and the bus steps were of varying heights with the handrails in different locations. Skills had to be re-taught with each new experience.

The solutions chosen to address these primary problems were to: a) teach motor skills when students are engaged in daily activities like transitioning

from place to place and using the bathroom; b) build motor skill training into every aspect of the student's life so that short, multiple practice sessions would be a daily occurrence; and c) teach in the actual environments where the skills would be utilized (Bidabe, 1998). The immediate concerns of insufficient instructional and practice time as well as poor generalization of skills led to changes in teaching strategies. Bidabe concluded, however, that these revised strategies would not necessarily lead to increased independence if individuals continued to practice prerequisite, developmental skills that often had little to no functional value. Thus, the MOVE Curriculum was developed to teach mobility skills required for everyday functioning.

The MOVE Curriculum accomplishes this not only by addressing *how* to teach, but also by providing a system for identifying *what* to teach. Rather than selecting skills from a developmental hierarchy based on a student's deficits, individuals using the MOVE Curriculum follow a top-down or ecological approach (Snell & Brown, 2000) to program planning. Instructional activities and basic skills are selected based on functional outcomes. Educational programs are then designed to teach individuals the skills necessary to be more independent and better integrated into their natural environments.

WHY DOES MOVE WORK?

In the summer of 1986, a pilot project implementing the MOVE Curriculum with 11 students over the age of seven with severe physical and cognitive disabilities was conducted at the Blair Learning Center in Kern County, California. This project was designed to address the needs of students with severe disabilities who showed a regression in basic skills as measured by typical developmental scales after they reached the age of seven. Previously therapy services often were discontinued for these students since it was assumed that they would not benefit from programming. Those who continued in therapy were no longer taught sitting, standing, and walking skills, but rather were taught to use wheelchairs and static equipment to replace these skills. In contrast, the MOVE pilot project provided intensive programming and adaptive support to teach sitting, standing, and walking skills even though these students appeared to be poor candidates for this type of programming.

As part of the MOVE Program, a transdisciplinary team approach was used to teach functional mobility skills through daily activities. By embedding skills into daily activities, students were able to receive intensive practice of functional mobility skills while participating in all classroom activi-

ties. During the eight-week program, students were taught functional sitting, standing, and walking skills using the MOVE Curriculum. Prior to the summer program, two students could sit or stand without support and three students could weight bear while standing. At the end of the eight weeks, nine students could sit in a chair without support, three students could walk with a walkerette, and one student could walk on his own.

Although this initial pilot project was anecdotal in nature, the results were encouraging to parents, teachers, and administrators about the potential of students with severe disabilities to make gains previously considered unattainable. With higher expectations of what might be possible, the Kern County School System continued to implement the MOVE Curriculum and document results. During the following fall, the teacher and therapists again implemented the MOVE Curriculum with 15 students placed at the Blair Learning Center and monitored their progress on functional mobility skills over the subsequent three years. Results indicated significant gains in sitting, standing, and walking skills (see Appendix D). These were students who because of their age and increased body weight had previously stopped making progress and in some cases had shown signs of regression (Kern County Superintendent of Schools, 1999).

With this initial indication of program effectiveness, it was clear that there was a need to further establish the foundations of the MOVE program. Empirical investigations into the effectiveness of MOVE have been initiated (e.g., Barnes, 1999). In the Barnes' study, the MOVE Curriculum was implemented using a multiple-baseline design across five subjects, ages 3 to 8, with severe, multiple disabilities who attended a public elementary school. All students demonstrated progress in functional mobility skills during the nine months of intervention or during maintenance over the following two years. Additional research in the area is currently being conducted.

UNDERLYING PRINCIPLES OF MOVE

Because the body of research on the MOVE Curriculum is in its early stages, it is necessary to identify other sources of support to validate the continued use of the program. Barnes and Whinnery (1997) reviewed the underlying principles of the MOVE Curriculum to establish the theoretical foundations and provide additional validation. They concluded that the MOVE Curriculum incorporates several accepted principles of development such as zone of proximal development, scaffolding, and partial participation. This review serves to: a) establish the sound principles embedded in the curriculum and b) help guide the focus of research so that relevant questions are

asked and a rationale exists for explaining the results (Gall, Borg, & Gall, 1996).

The zone of proximal development concept views development as evolving through mediated learning experiences designed to guide individuals to new skills before they appear “ready.” This allows educators to focus on the *potential* level of development in addition to the *actual* level of development (van Geert, 1994). By focusing on potential levels of development, practitioners will have a greater likelihood for higher expectations.

The MOVE Curriculum incorporates the zone of proximal development principle by identifying a student’s actual level of development through an assessment of functional mobility skills. The potential level of development is addressed through the selection of functional outcome goals. These goals are selected based upon the individual and family’s needs and desires regardless of the student’s apparent readiness.

Progress through the zone of proximal development occurs when a more skilled adult or peer provides guidance and assistance from the actual level of development to the potential level of development. This support, known as scaffolding, is particularly important for individuals with severe disabilities who require intensive prompting and support in the acquisition of new skills. The MOVE Curriculum provides a scaffolding system to allow consistent monitoring of prompts to discourage unnecessary reliance on assistance and to promote the attainment of chosen goals.

Within the MOVE Curriculum, scaffolding can allow individuals to perform higher level tasks that they might not be able to perform independently. For example, although an individual does not have the “prerequisite” skills for walking, a student can be functionally mobile through the use of a gait trainer, an adaptive walker, or adult assistance. MOVE includes a comprehensive support system to allow students to perform higher level tasks as well as a plan for fading necessary prompts. The previously described prompt categories (i.e., prompts for sitting, standing and walking, and arm control) and classifications (i.e., type of assistance, prompt position, and amount of assistance) allow team members to identify individualized prompt plans according to a student’s current needs. The student who requires the use of a gait trainer for walking might also require an individualized plan for additional support at the trunk, forearms, hips, and legs. Eventually, as the child increases strength from being upright and mobile, the educational team would look for opportunities to reduce prompts. With time, all prompts may be able to be faded allowing the child to become an independent walker. However, it is recognized that some students may always need some level of support to achieve their highest level of independence.

Another principle underlying the MOVE Curriculum is partial participation (Baumgart et al., 1982). Use of partial participation allows individuals to be involved, to the maximum extent possible, in relevant, meaningful activities rather than to be excluded from activities based on a lack of mastery of prerequisite skills. An example of this exclusion is when a student is taken from his classroom to the library in his wheelchair rather than using a walker because he is not able to walk the entire distance. Instead of denying the student the opportunity for meaningful participation and mobility skill practice, the child can be allowed to begin the trip in his wheelchair and then walk with support for the remaining distance. Partial participation in this activity allows the student to be actively involved in the transition, to be more like his peers, and to continually work on increasing his walking skills rather than waiting until he is able to walk the entire distance.

ALIGNMENT WITH CURRENT PRACTICES

Support model. Current educational practices for students with severe disabilities promote the use of a support model that emphasizes an individual's future potential rather than an individual's limitations. Earlier practices that focused on deficits often limited an individual's access to environments and activities because of the lack of prerequisite skills (Brown et al., 1979). However, a more optimistic view of an individual's potential has led to a top-down approach to program planning that provides a framework for identifying adult outcomes, determining current levels of functioning, and identifying supports needed to achieve the outcomes. This model incorporates the concept of "place then train" which allows individuals to learn in the environments in which the actual skills will be used (Snell & Brown, 2000). An example of this would be the young adult with limited mobility who is supported to walk while grocery shopping. Shopping trips may be brief at first, or a motorized cart may be used for part of the activity. However, as mobility improves, the individual is permitted to walk for increasingly longer portions of the activity. The individual is not held back because of the lack of independence, instead he/she is supported and allowed to problem solve within the natural demands of the setting and in a relevant environment.

Integrated Therapy. Closely related to the concept of "place then train," which aligns educational goals with the requirements of the students' natural environments, is the concept of integrated therapy. Integrated therapy delivers educational and related services in natural settings where skills will be functional and performance meaningful for the individual student (Dunn, 1991; Rainforth & York-Barr, 1997; Sternat, Messina, Nietupski, Lyon, & Brown, 1977). This approach to service delivery also has the characteristic of

being team-based in that parents, teachers, and therapists collaborate to assess the student, set and prioritize goals, and implement intervention. This is accomplished using an ecological approach to program planning (Brown et al., 1979). The team develops the IEP together and sets goals and priorities through consensus. In this way all team members are aware of the educational and therapeutic goals and how these might be embedded into the child's natural activities.

The integrated therapy approach breaks from the more traditional multidisciplinary model in which team members conduct assessments and set discipline-specific goals in relative isolation (Orellove & Sobsey, 1996). Although in the traditional approach all involved educators and therapists may meet with the parents as a team to develop the IEP, each member of the team is responsible only for implementing his or her portion of the IEP. In many cases, this is done with little communication between team members and little understanding of the other members' goals for the student. This can lead to fragmented services and fragmented ownership of the student's program (Giangreco, 1995). In other words, a specific therapeutic goal may be addressed only when the child is receiving direct therapy services from a particular professional. At other times this goal may not be addressed directly.

The MOVE Program recognizes the benefits of a collaborative team approach over a multidisciplinary approach. Integrated therapy is an essential component of the MOVE Curriculum in that the parents are full partners with teachers and therapists in assessing the student's needs using the TDMMT, setting educational and mobility goals, and providing practice in natural environments. A MOVE program is developed based on the family's priorities and needs. The MOVE Curriculum, therefore, becomes an integral part of the child's life as therapy practice is easily integrated into a child's normal activities within his/her natural environments. Mobility training stops being an isolated service that is conducted three times a week in a therapy room and now occurs as a natural part of how the child gets to and from the lunch room, stands and sits during classroom activities, and transfers into and out of the bathtub.

As the integration of mobility training into normal activities becomes a natural part of the school routine, it then can easily be extended beyond the school. Parents, who are full partners on the team, become increasingly skilled at identifying opportunities for their child to practice mobility skills. This results in the integration of MOVE into all aspects of the child's life. The practice of mobility skills outside of the classroom not only reinforces the school-based goals, but also increases the child's independence and

decreases the need for support. This, in turn, facilitates the child's participation in home and community activities.

CONCLUSION

Mobility Opportunities Via Education (MOVE) is a curriculum that provides a systematic approach to teaching functional mobility skills. Based on the support model concept, MOVE encourages programming that emphasizes functional outcomes as opposed to skill deficits. Although functional mobility is the primary focus of the MOVE Curriculum, the program supports activity-based learning to promote holistic teaching rather than isolated skill instruction. Teaching occurs within natural environments whether at home, school, or in the community to facilitate the generalization of skills. The continual practice of skills in all environments naturally leads to an integrated team approach. The family and the school staff collaborate to share information, train one another, and identify as many practice opportunities as possible throughout the student's life. Functional outcome goals become the primary focus and adaptations and supports are provided to meet these goals. As MOVE becomes an integral part of an individual's life, abilities rather than deficits are emphasized leading to increased opportunities and an overall improvement in the quality of life.

APPENDIX A

Summary of Test Results from the Top-Down Motor Milestone Test™

M.O.V.E.
Top-Down Motor Milestone Test™



SUMMARY OF TEST RESULTS

NAME _____

DATE _____

1. Fill in squares representing the current skill levels.
2. Fill in all squares to the right of the current skill levels.
3. Circle skills to be addressed next.

	GRAD LEVEL		LEVEL I				LEVEL II				LEVEL III		
	A.1		A.2	A.3			A.4	A.5	A.6		A.7		
A. MAINTAINS A SITTING POSITION	B.1	B.2	B.3	B.4	B.5	B.6	B.7	B.8	B.9	B.10	B.11	A.7	
B. MOVES WHILE SITTING	C.1		C.2				C.3	C.4			C.5	C.6	
C. STANDS	D.1	D.2	D.3	D.4			D.5	D.6			C.5	C.6	A.7
D. TRANSITIONS FROM SITTING TO STANDING	E.1	E.2	E.3	E.4			E.5	E.6			C.5	C.6	A.7
E. TRANSITIONS FROM STANDING TO SITTING	F.1		F.2				F.3				C.5	C.6	
F. PIVOTS WHILE STANDING	G.1	G.2	G.3				G.4	G.5			G.6	C.5	C.6
G. WALKS FORWARD	H.1		H.2				H.3				G.6	C.5	C.6
H. TRANSITIONS FROM STANDING TO WALKING	I.1		I.2				I.3				G.6	C.5	C.6
I. TRANSITIONS FROM WALKING TO STANDING	J.1		J.2				J.3				J.4	C.5	C.6
J. WALKS BACKWARD	K.1	K.2	K.3	K.4			E.3				C.5	C.6	
K. TURNS WHILE WALKING	L.1		L.2				L.3	G.4	C.5				
L. WALKS UP STEPS	M.1		M.2				M.3	E.4	C.5				
M. WALKS DOWN STEPS	N.1		N.2				N.3	G.4	C.5				
N. WALKS ON UNEVEN GROUND	O.1		O.2				O.3	G.4	C.5				
O. WALKS UP SLOPES	P.1		P.2				P.3	G.4	C.5				
P. WALKS DOWN SLOPES													

PREREQUISITE SKILLS FROM OTHER SECTIONS ARE INDICATED BY ITALICIZED LETTERS AND NUMBERS

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APPENDIX B

Sample of a skill from the Top-Down Motor Milestone Test showing the levels of the skill.

WALKING FORWARD**G**

	GRAD LEVEL			
		LEVEL I	LEVEL II	LEVEL III
G.1. Can walk forward a minimum of 20 feet without assistance.	<input type="checkbox"/>			
G.2. Can walk a minimum of 1,000 feet with one hand held.	<input type="checkbox"/>			
G.3. Can walk a minimum of 300 feet with one or both hands held or with a walker.		<input type="checkbox"/>		
G.4. Can move legs reciprocally for a minimum of 10 feet while bearing weight when another person assists with shifting weight and maintaining balance.			<input type="checkbox"/>	
G.5. Can move legs reciprocally for a minimum of 20 feet while being supported by a front leaning walker or by another person.			<input type="checkbox"/>	
G.6. Can tolerate fully prompted reciprocal leg movements while being supported in a front leaning walker or by another person.				<input type="checkbox"/>

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APPENDIX C

Sample of Prompt Reduction Plans from the MOVE Curriculum



PROMPT REDUCTION PLAN



NAME _____ GOALS AND PARAMETERS _____
 BEGINNING DATE _____
 ENDING DATE _____



	ACHIEVED					ACHIEVED					ACHIEVED					TARGET/GOAL								
	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date				
	0	1	2	3	4	5	0	1	2	3	4	5	0	1	2	3	4	5	0	1	2	3	4	5
A. TOP DOWN																								
B. CENTER OUT TRUNK																								
C. BODY SEGMENT																								
D. AMOUNT OF PROMPT																								
E. TYPE OF PROMPT																								
F. PROMPT POSITION																								

A. Top Down Prompts

B. Center Out Prompts

C. Body Segment Control

D. Amount of Prompt

E. Type of Prompt

F. Prompt Position

TOTAL BODY 5

SHOULDER 4

TRUNK 3

HIPS 2

LEGS 1

Trunk

6 - SHOULDER OR TRUNK

4 - UPPER ARM

3 - ELBOW

2 - FOREARM

1 - HAND

1 GUIDANCE

2 BALANCE

3 SUPPORT

4 FLEXIBLE PROMPT (CLOTH OR STRAP)

5 ANOTHER PERSON'S HAND

6 MECHANICAL OR SOLID PROMPT

1 BEHIND

2 IN FRONT

3 BEHIND

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APPENDIX D**Results from the Three-Year Pilot Study of MOVE conducted in Kern County, California****PROGRAM DATA**

	Sept. 1986	Aug. 1989
1. Sits on a classroom chair for 30 minutes. (This is the average length of time for any classroom activity and for most meals.)	9	14
2. Sits on stool for five minutes. (If a person can sit this long without support, the caregiver has ample time to get the person off the bed, the edge of the bathtub, etc.)	9	12
3. Bears full weight on feet for one minute. (In one minute, a person's diaper can be removed or clothing adjusted and the person can be placed on the toilet. The person can also stand to have the diaper reapplied.)	6	13
4. Pulls to a standing position with an aide. (A person who can assist in getting to a standing position does not have to be lifted.)	3	12
5. Maintains a standing balance for one minute when stabilized at the knees. (A person who can maintain hip, trunk, and head balance while leaning against a table or counter, has free arm movement for brushing teeth, washing hands, etc.)	0	10
6. Walks five feet using reciprocal steps when balance is provided by a front leaning walker or by another person. (The ability to walk a minimum of five feet gives access to almost any toilet or small space inaccessible to a wheelchair.)	5	14
7. Gets up from a chair, walks 20 feet, seats self in a chair without assistance. (A person who has achieved these skills will have independence within the home environment.)	0	2
8. Some functional use of upper extremities. (Functional use is defined as self-feeding, wheelchair movement, or purposeful grasp and hold.)	6	13

Note. From MOVE: Mobility Opportunities Via Education (p. 1.16), by K. F.

Blanton, 1990, Bakersfield, CA: Kern County Superintendent of Schools.

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INFORMATION FOR AUTHORS

PHYSICAL DISABILITIES: EDUCATION AND RELATED SERVICES THE DIVISION FOR PHYSICAL AND HEALTH DISABILITIES

PDERS seeks to publish articles that contribute to the field of knowledge about education and related services for individuals with physical, orthopedic or health impairments. The following are considered for publication: empirical research; theoretical perspectives; case studies which address promising practices; innovative instructional practices; and reviews of relevant books, materials, media and software.

SUBMISSIONS

Manuscripts should be submitted to: Dr. Barbara J. Kulik, 3380 Country Club Drive, Glendale, CA 91208-1718 (bkulik@csun.edu). Three copies of the manuscript, together with a diskette or email attachment of the manuscript in either WordPerfect or MicrosoftWorks in IBM PC-compatible format, should be submitted for review. All tables and figures should be included with each copy of the manuscript.

PREPARATION

The entire manuscript (title page, abstract, text, tables, figures, and references) should be double-spaced on 8 1/2 x 11-inch paper with at least a 1-inch margin on all sides. A cover sheet should include title, author(s) name and affiliation (including statements of credit or research support), address, telephone number and email of the author to whom correspondence should be directed, and a running head. The abstract should precede the text on a separate sheet of paper and should bear the full title of the article. The running head should appear on all subsequent pages.

Tables and figures should be numbered by separate series and placed at the end of the manuscript. Provide brief notes within the text to indicate where each table or figure is to appear.

Overall style should conform to that described in the *Publication Manual of the American Psychological Association*, Fourth Edition, 1994.

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EFF-089 (3/2000)